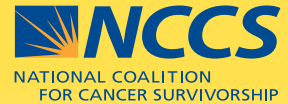


Cancer Survival Toolbox®

Resource Booklet



Newly Revised and Updated

- Audio CDs that let you **listen and learn** from survivors as they share their experiences, skills, and resources
- Full of **practical tips and strategies**
- Information for people at **any stage of cancer survivorship**—newly diagnosed, undergoing treatment, transitioning to new treatments or off treatment, and beyond...
- **Get started today!**



"This Toolbox has helped me feel more in control. I know where to start and don't feel so alone."

—Joel S.*




"The most helpful and realistic of the resources I found."

—Claudia J.*



"The Toolbox helped me in communicating with my doctors, with decision-making. It also gave me hope. A wonderful resource!"

—Dwain R.*



Did you find this program useful? Your feedback will help us provide the best information to other cancer survivors. Please take the survey online at www.canceradvocacy.org/toolbox/survey, or call 877-NCCS-YES (877-622-7937).

The *Cancer Survival Toolbox* is provided free of charge and used each year by thousands of people in cancer centers, hospitals, support groups, corporate wellness programs, community organizations, and professional societies. Please help make the program available by donating online at www.canceradvocacy.org/donate.



The First Step to Cancer Survival™



Program Highlights

- **Communication skills** for survivors
- Tips on **finding information** from many sources
- Techniques for **making decisions** about treatment and other issues
- Real scenarios showing survivors **solving problems**
- Strategies for **negotiating** with providers, insurers, employers, and others
- **Standing up for your rights** using self-advocacy skills across all stages of cancer survivorship
- Cancer-related resources (organizations, phone numbers, websites, books, etc.)

Content Development Partners



Supporting partners who made this project possible through unrestricted grants:



NOT FOR SALE

The Toolbox is provided as a free program thanks to the generous support of our partners.

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877-NCCS-YES (877-622-7937)

Fax: 301-565-9670

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www.canceradvocacy.org

www.canceradvocacy.org/toolbox

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I. Introduction

Welcome to the *Cancer Survival Toolbox*® Resource Booklet!

This booklet is designed to be used by cancer survivors and their loved ones at *any* stage of cancer survivorship. By “survivors,” we mean *anyone* diagnosed with cancer, from the time of their diagnosis, through the rest of their lives.

The award-winning *Cancer Survival Toolbox* is a self-learning audio program created by the National Coalition for Cancer Survivorship (NCCS), along with cancer survivors and leading cancer organizations, to help you develop practical skills that you can use on a day-to-day basis as you deal with cancer diagnosis and treatment for yourself or a loved one.

Stories From Survivors, Their Loved Ones, and Their Healthcare Teams

On the CDs in this Toolbox you will find conversations with survivors like you and their loved ones and doctors, nurses, social workers, and other healthcare professionals that have helped them. These survivors have gone through things that may be similar to what you are experiencing. Through their stories, you will receive practical information that can help you make the best decisions and take the best care of yourself.

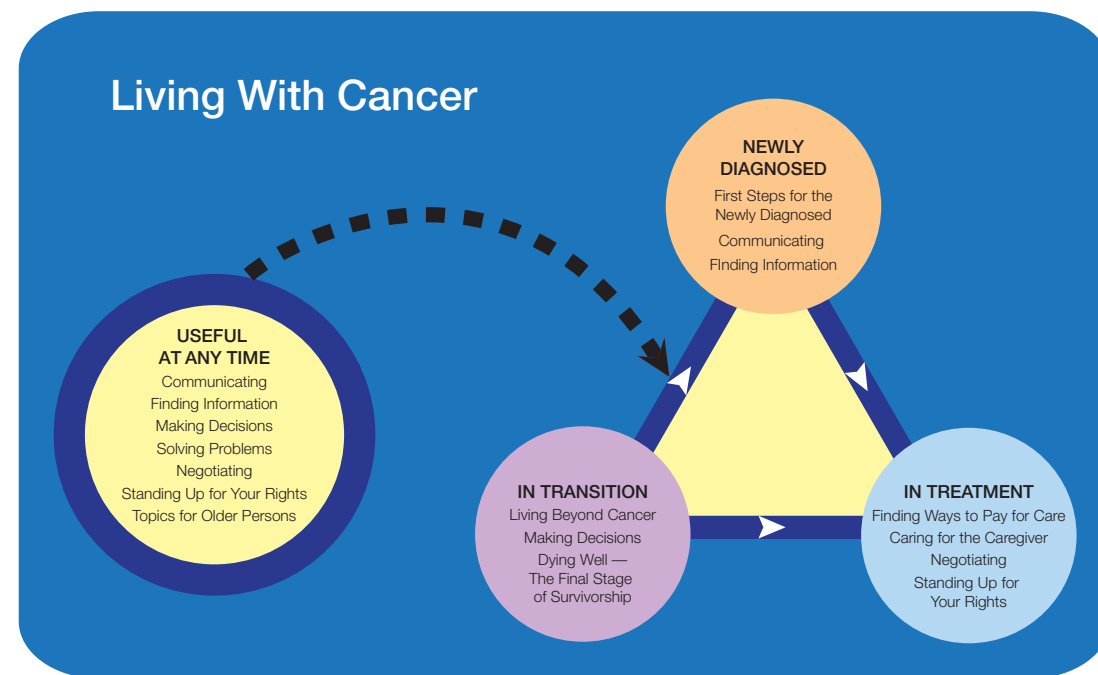
The Resource Booklet you are currently holding lists multiple resources (organizations, phone numbers, websites, books, etc.), including those mentioned in the CDs. Everything is in one easy-to-access place.

Practical Information for Wherever You Are in Your Cancer Survivorship

Don't feel that you need to take in all of the information here at once! The CDs and Resource Booklet are designed so you can access what you need, *when* you need it. And no matter where you are in your journey—whether newly diagnosed, actively undergoing treatment, finished with treatment, or in some sort of transitional stage—there is information here for you.

If you don't know where to start, the chart on the following page can help match your situation to the CDs/parts of the Resource Booklet that may be most useful now. After you've listened to the program(s) of interest, you can also keep the Toolbox, so that you can access new information if different situations arise in the future.

Select Programs That May Be of Most Help to You Now



Note: Details about individual programs can be found on the pages that follow.

We hope that you find this Resource Booklet to be of help as you move forward in your cancer survivorship.

To order additional copies of this FREE program, or to order the program in Spanish, please contact the National Coalition for Cancer Survivorship at 877-NCCS-YES (877-622-7937) or www.canceradvocacy.org/toolbox.

II. Additional Cancer Survival Toolbox Programs/Resources

Cancer Survival Toolbox Programs for Specific Diseases

Additional Toolbox programs not contained on these CDs include:

- Living With Multiple Myeloma
- Living With Non-Hodgkin Lymphoma
- Living With Chronic Lymphocytic Leukemia
- Living With Chronic Myelogenous Leukemia

Order or listen to these Toolbox programs by visiting www.canceradvocacy.org/toolbox or calling 877-NCCS-YES (877-622-7937).

Programs Are Also Available in Spanish and Chinese, and in Other Formats

Visit www.canceradvocacy.org/toolbox to:

- Listen to, order CDs, or read transcripts of these programs in English or Spanish (CDs can also be ordered by calling 877-NCCS-YES [877-622-7937])
- Read transcripts of the Basic Skills programs in Chinese
- Gain access to Toolbox programs via iTunes®

III. Resources for Healthcare Professionals

Great Resource for You and Your Patients—Especially the Newly Diagnosed

The *Cancer Survival Toolbox* can be given to your patients, used by patient navigators, offered in patient resource libraries, provided at survivorship programs and conferences, and listened to in support group settings, among other uses.

A special note: We at NCCS have received a great deal of feedback from survivors about the utility of the *Cancer Survival Toolbox* when it is provided very soon after diagnosis. Many healthcare professionals don't want to overwhelm their patients with too much information when first diagnosed, but because the Toolbox is structured so that patients may listen only to the programs of interest, it can provide crucial information at a time when patients may need it most. We recommend that the Toolbox be provided to patients early in their cancer journey.

Free Facilitator's Manual Available

A free Facilitator's Manual is available to healthcare providers. This valuable resource can help you incorporate the Toolbox into a variety of settings. To obtain your copy, visit www.canceradvocacy.org/toolbox (click the "For Healthcare Professionals" tab), or call 877-NCCS-YES (877-622-7937).

IV. Toolbox Programs on Basic Skills

Communicating

Program length: 30 minutes

Communicating means letting someone else know clearly what you think and feel, and also learning what the other person thinks and feels.

After listening to this Toolbox program, you will be better prepared to:

- Assert yourself or state positively what you want and need
- Make “I” statements by saying “I think” or “I feel” instead of saying “you should”
- Listen actively and check the message. This means listening carefully, showing the other person you are listening, and checking to see if what you heard is what the person meant to say
- Match verbal with nonverbal communication, that is, match your words to your actions and facial expressions
- Express your feelings by letting others know how you feel as well as what you think

Resources for Communicating

CancerCare

800-813-HOPE (800-813-4673)

www.cancercare.org

Provides one-on-one counseling, telephone support groups, and referral to other services.

Clark EJ (ed). (2010). *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fifth Edition. Available at www.canceradvocacy.org or 877-622-7937.

Harpham WS. (2003). *Diagnosis, Cancer: Your Guide to the First Months of Survivorship*. New York, NY: W.W. Norton & Co., Inc. Third Edition.

Finding Information

Program length: 27 minutes

Finding Information explains how to use many of the different resources available to find information that will help you understand your kind of cancer and its treatment.

After listening to this Toolbox program, you will be better prepared to:

- Find good information on the kind of cancer you have and on the types of treatment that offer the best records for success
- Pick the experts you respect and trust to be part of your healthcare team
- Know when and how to seek a second opinion
- Look for what is new in the treatment of your kind of cancer
- Know that the decisions you have made about your cancer and its treatment are based on the right kind and right amount of information

Finding Information on the Internet

On the Internet, cancer survivors can get information available throughout the world, all at the touch of a few keystrokes on a computer in their home, library, or community center. It can be hard to find your way around the Internet at first. You may need to ask for help. A word of caution: There is a great deal of very helpful, reliable, factual information available on the Internet, but there is also a lot of misinformation. It is important to be sure your sources are reliable and to check information further. The most reliable medical information will come from well-known cancer organizations, research facilities, hospitals, libraries, government agencies, and professional journals.

There are many good books to help you get comfortable with using the Internet. Also, many of the companies that provide Internet access offer free classes to help beginners learn how to use the Internet. Community colleges, senior centers, information specialists in community or hospital libraries, or the cancer information specialist in a cancer resource center may also be able to provide some beginning instruction to help you get started.

Resources for Finding Information

American Cancer Society (ACS) National Cancer Information Center

800-ACS-2345 (800-227-2345)

www.cancer.org

Provides information about specific cancers and has resources for supportive care and services around the country.

Harpham WS. (2003). *Diagnosis, Cancer: Your Guide to the First Months of Survivorship*. New York, NY: W. W. Norton & Co., Inc. Third Edition.

Morra M, Potts E. (2003). *Choices*. New York, NY: HarperCollins Publishers, Inc.

National Cancer Institute (NCI) Cancer Information Service

800-4-CANCER (800-422-6237)

www.cancer.gov

Provides access to many types of information resources covering different cancers, treatments, and supportive care.

NCI Physician Data Query (PDQ®)

www.cancer.gov/cancertopics/PDQ

Provides summaries on different cancer topics for patients and healthcare professionals.

Making Decisions

Program length: 28 minutes

Making Decisions is designed to help you identify how you make decisions, how your style of decision making can work or be improved, and how you can weigh the pros and cons of deciding about cancer treatment.

After listening to this Toolbox program, you will be better prepared to:

- Identify how you prefer to make decisions about cancer and cancer treatment
- Find out the benefits of getting a second opinion to help you make decisions
- Identify how much time you have to make a decision
- Weigh the pros and cons in making a decision about cancer treatment
- Understand that you are an individual, NOT a cancer statistic

Resources for Making Decisions

CancerCare

800-813-HOPE (800-813-4673)

www.cancercare.org

Provides one-on-one counseling, telephone support groups, and referral to other services.

Galsky M. (2009). *Everything You Need to Know about Cancer*. Sudbury, MA: Bartlett Publishing, LLC.

Harpham WS. (2003). *Diagnosis Cancer: Your Guide Through the First Few Months of Healthy Survivorship*. New York, NY: W. W. Norton & Company. Third Edition.

Morra M, Potts E. (2003). *Choices*. New York, NY: HarperCollins. Fourth Edition.

Solving Problems

Program length: 30 minutes

Solving Problems describes how to identify and follow the steps needed to solve a difficult situation in your life or daily activity.

After listening to this Toolbox program, you will be better prepared to:

- Identify and define the problem
- Gather information
- Plan your action
- Carry out your plan
- Evaluate your plan and make necessary changes

Resources for Solving Problems

CancerCare

800-813-HOPE (800-813-4673)

www.cancercare.org

Provides one-on-one counseling, telephone support groups, and referral to other services.

Clark EJ (ed). (2010). *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fifth Edition. Available at www.canceradvocacy.org or 877-622-7937

Harpham WS. (2003). *Diagnosis Cancer: Your Guide Through the First Few Months of Healthy Survivorship*. New York, NY: W. W. Norton & Company. Third Edition.

Negotiating

Program length: 30 minutes

Negotiating means talking with people involved in your healthcare so that you can get what you need to have the best quality of life possible.

After listening to this Toolbox program, you will be better prepared to:

- Listen and communicate effectively
- Identify the values that are the principles and standards by which you live
- Set your personal limits—the boundaries of behavior that you will not cross
- Learn to set emotions aside when negotiating
- Visualize more than one solution to any problem

Resources for Negotiating

Calder KJ, Pollitz K. (2006). *What Cancer Survivors Need to Know About Health Insurance*. Silver Spring, MD: National Coalition for Cancer Survivorship. Sixth Edition. Available at www.canceradvocacy.org.

Clark EJ (ed). (2010) *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fifth Edition. Available at www.canceradvocacy.org.

Clark EJ. (2008). *You Have the Right to Be Hopeful*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition. Available at www.canceradvocacy.org.

Donaldson MC, Frohnmayer D (foreword). (2007). *Negotiating for Dummies*. Hoboken, NJ: Wiley Publishing, Inc.

Hoffman B (ed). (2010). *Working It Out: Your Employment Rights as a Cancer Survivor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Ninth Edition. Available at www.canceradvocacy.org.

Self-Advocacy: A Cancer Survivor's Handbook. (2009). Silver Spring, MD: National Coalition for Cancer Survivorship. Second Edition. Available at www.canceradvocacy.org.

Standing Up for Your Rights

Program length: 23 minutes

Standing Up for Your Rights means learning to actively do something in your own best interest. This is also known as *self-advocacy*.

After listening to this Toolbox program, you will be better prepared to:

- Feel more in control about your life
- Build confidence to face challenges that seem too difficult to overcome
- Reach out to others, such as asking to talk to someone who is in a situation similar to yours
- Feel hopeful rather than hopeless and helpless

Resources for Standing Up for Your Rights

Cancer Legal Resource Center

866-THE-CLRC (866-843-2572)

www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm

Promotes the rights of people with disabilities, and the public interest in and awareness of those rights, by providing legal and related services.

Clark EJ (ed). (2010) *Teamwork: The Cancer Patient's Guide to Talking with Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fifth Edition. Available at www.canceradvocacy.org.

Clark EJ, Stovall E. (1996). Advocacy: The cornerstone of cancer survivorship. *Cancer Practice*, vol 4, pgs 239-244.

Facing Forward: Making a Difference in Cancer. (2010). Bethesda, MD: National Cancer Institute. Available at www.cancer.gov/ or 800-4-CANCER (800-422-6237).

Patient Advocate Foundation

800-532-5274

www.patientadvocate.org

Provides free mediation and arbitration services.

Self-Advocacy: A Cancer Survivor's Handbook. (2009). Silver Spring, MD: National Coalition for Cancer Survivorship. Second Edition. Available at www.canceradvocacy.org.

V. Toolbox Programs on Special Topics

First Steps for the Newly Diagnosed

Program length: 1 hour 8 minutes

First Steps for the Newly Diagnosed refers to the information that needs to be gathered and the decisions that need to be made in the initial days and weeks after you are diagnosed with cancer. In this program, we offer practical guidelines designed to help you take those first steps toward successfully meeting the challenges that a cancer diagnosis can impose.

After listening to this Toolbox program, you will be better prepared to:

- Select the members of your cancer care team
- Work with your team to gather the information needed to make informed decisions
- Decide on an initial treatment plan
- Learn what you need to know about your insurance policy (or where to go for help if you are underinsured or uninsured)
- Tell people about your diagnosis
- Identify and ask for the help and support you'll need

Note: A copy of the Distress Thermometer, an important component of this program, can be found on page 34 of this booklet.

Resources for First Steps for the Newly Diagnosed

Note: You can find additional information and resources in this booklet's Clinical Trials section (pg 30).

Ackermann A, Ackermann A. (2001). *Our Mom Has Cancer*. Atlanta, GA: American Cancer Society.

American Board of Medical Specialties (ABMS)

312-436-2600

www.abms.org/

Helps people find doctors who are ABMS Board-Certified Specialists.

American Journal of Nursing (April 2007): The Cancer Survivor's Prescription for Living

www.nursingcenter.com/ajncancersurvivors

This article contains a care-planning model, which can be used as is, or adapted to closely fit your needs.

American Society of Clinical Oncology (ASCO)

888-651-3038

www.cancer.net

Offers educational information, guidance, and support to people who are affected by cancer.

CancerCare

800-813-HOPE (800-813-4673)

www.cancercare.org

A national organization that provides a toll-free counseling line and educational programs. Counseling and some materials are available in Spanish. All services are free of charge.

Cancer Support Community (formerly The Wellness Community and Gilda's Club)

888-793-9355

www.cancersupportcommunity.org

More than 20 centers in the United States provide free support and education to people with cancer and their loved ones. Online services include support groups, a resource library, a nutrition center, and its "mind/body room."

CaringBridge

www.caringbridge.org/

Offers free, personalized websites that connect family and friends during a serious health event.

Circle of Sharing™

<https://circleofsharing.cancer.org/>

An American Cancer Society resource that helps cancer patients and their caregivers get personalized information about the disease, and share that information with family and friends.

Clark EJ (ed). (2010) *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fifth Edition. Available at www.canceradvocacy.org.

Clark EJ. (2008). *You Have the Right to Be Hopeful*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition. Available at www.canceradvocacy.org

Federation of State Medical Boards

817-868-4000

www.fsmb.org/directory_smb.html

A directory of state medical boards, which provide access to records of lawsuits against doctors and review compliance with continuing education credits.

Fertile Hope

866-965-7205

www.fertilehope.org

A national LIVESTRONG initiative that provides reproductive information, support, and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

Filigenszi, C. (2009). *Let My Colors Out*. Atlanta, GA: American Cancer Society.

Greenfield N. (2005). *When Mommy Had a Mastectomy*. Savage, MD: Bartleby Press.

Harpham WS. (2003). *Diagnosis: Cancer. Your Guide Through the First Few Months of Healthy Survivorship*. New York, NY: W. W. Norton & Company.

Harpham WS. (2004). *When a Parent Has Cancer: A Guide to Caring for Your Children and Becky and the Worry Cup*. New York, NY: HarperCollins.

Healy B. (2007). *Living Time: Faith and Facts to Transform Your Cancer Journey*. New York, NY: Bantam Books.

HealthGrades

www.healthgrades.com/

A leading independent nonprofit organization that rates physicians, hospitals, and nursing homes.

Health Privacy Project

www.cdt.org/issue/health-privacy

Provides information about state laws and how to obtain copies of medical records.

Journey Forward

877-NCCS-YES (877-622-7937)

www.journeyforward.org

Offers free software that enables healthcare professionals to create a treatment summary and post-treatment plan.

Kohlenberg S. (1993). *Sammy's Mommy Has Cancer*. Washington, DC: Magination Press.

Lance Armstrong Foundation

866-467-7205 or 866-673-7205

www.livestrong.org

Offers LIVESTRONG SurvivorCare—a cancer support section on its website. Services include one-on-one support, counseling, and referrals to local resources, help with understanding insurance and financial issues, and clinical trials matching.

Medicare Hotline

800-MEDICARE (800-633-4227) or 877-486-2048 (TTY)

National Cancer Institute (NCI) Cancer Information Service

800-4-CANCER (800-422-6237)

www.cancer.gov

Offers “Your Pathology Report” and information about specific cancers.

National Comprehensive Cancer Network (NCCN)

215-690-0300

www.nccn.com/

Provides treatment summaries for people with cancer.

R. A. Bloch Cancer Foundation

800-433-0464

www.blochcancer.org

A nonprofit organization that provides a list of multidisciplinary second opinion services.

Self-Advocacy: A Cancer Survivor's Handbook. (2009). Silver Spring, MD: National Coalition for Cancer Survivorship. Second Edition. Available at www.canceradvocacy.org or 877-NCCS-YES (877-622-7937).

Silver A, Silver E, Silver AR. (2007). *Our Dad Is Getting Better*. Atlanta, GA: American Cancer Society.

Thiboldeaux K, Golant M. (2007). *The Total Cancer Wellness Guide: Reclaiming Your Life After Diagnosis*. Dallas, TX: BenBella Books.

Topics for Older Persons

Program length: 1 hour 15 minutes

Cancer is a common problem for many older persons, but simply being older should not add to the burden of the disease. This audio program, *Topics for Older Persons*, focuses on issues that have specific meaning for older cancer survivors. Examples of these issues include finding quality cancer care despite your age and other health problems, getting help paying for medications you need, and standing up for your rights in a healthcare system that sometimes discriminates against the older person.

After listening to this Toolbox program, you will be better prepared to:

- Communicate about your condition
- Find information about your condition
- Make decisions
- Solve problems
- Negotiate about your treatment and care
- Stand up for your right to make informed decisions

Resources for Topics for Older Persons

AARP (American Association of Retired Persons)

888-OUR-AARP (888-687-2277)

www.aarp.org/health

Provides general information on health, wellness, advance directives, Medicare, and financial concerns.

American Geriatrics Society

212-308-1414

www.americangeriatrics.org

An organization of health professionals devoted to improving the health, independence, and quality of life of all older people.

Council of Better Business Bureaus

703-276-0100

www.bbb.org/us/

Can be used to learn whether a business is legitimate, before paying for a service or merchandise.

Eldercare Locator

800-677-1166

www.eldercare.gov

A public service of the U.S. Administration on Aging. Provides a national number where staff can help you find support resources in your area.

Aging With Dignity and Five Wishes®

888-5-WISHES (888-594-7437)

www.agingwithdignity.org

Affirms and safeguards the human dignity of individuals as they age and promotes better care for those near the end of life. *Five Wishes* helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. It deals with all of a person's needs: medical, personal, emotional, and spiritual.

Life Insurance Settlement Association

407-894-3797

www.thevoiceoftheindustry.com

Provides a list of viatical companies that will buy your life insurance policies under certain conditions.

Questions and Answers When Looking for an Elder Law Attorney. This pamphlet covers issues such as where to find an attorney, what questions to ask, how to discuss fees, and more. To obtain a copy, send a self-addressed, stamped envelope (legal size) to the address below:

National Academy of Elder Law Attorneys

1604 North Country Club Road

Tucson, AZ 85716

520-881-4005

www.naela.com

Williams ME. (1995). *The American Geriatrics Society's Complete Guide to Aging and Health*. New York, NY: Harmony Books.

Finding Ways to Pay for Care

Program length: 1 hour 13 minutes

People who have no health insurance or have problems with their insurance face special barriers to getting quality cancer care. But, while finding care when you do not have insurance coverage is difficult, it is not impossible. If you need help paying for your medications, there are several options available. First, your state may have a pharmaceutical assistance program that will help you pay for the drugs you need. Also, most of the large drug companies have what is called an "Indigent Drug Program." These programs help provide medications to people who cannot afford them. Individuals cannot apply directly for these programs. However, your doctor, nurse, or social worker can contact them and help get your drug costs covered. Contact your local or state department on aging to see if such a program is available in your state. In addition, contact *Needy Meds* (www.needymeds.org) for information about getting medications from pharmaceutical companies.

The stories you will hear in this program offer hope and encouragement that insurance problems need not stand in the way of finding and getting good cancer care. After listening to this Toolbox program, you will better understand:

- The effect of insurance on cancer care
- What to do when you have no insurance
- Medicare benefits
- Hospice care and how to evaluate it
- Medicaid
- Veterans Affairs benefits
- Public and private community resources
- Your life insurance
- Private insurance and gaps in coverage
- Getting and paying for prescription medicines
- Federal laws and healthcare rights

Help With Paying for Care

If you don't have insurance, get help through a social worker and/or a financial counselor at your local hospital or cancer treatment center. The case manager will contact you and begin working with you to ensure that your questions are answered and your needs are met. Ask your case manager for his or her direct-dial telephone extension so you can avoid time-consuming menu selections and recordings when you call the case manager in the future. The Cancer Support Community website, www.thewellnesscommunity.org, also offers information.

Resources for Finding Ways to Pay for Care

AARP (American Association of Retired Persons)

888-OUR-AARP (888-687-2277)

www.aarp.org/health

Provides general information on health, wellness, advance directives, Medicare, and financial concerns.

American Cancer Society/National Endowment for Financial Education. (2008). *Advanced Illness: Financial Guidance for Cancer Survivors and Their Families*. Available at ww2.cancer.org/downloads/MIT/Advanced_Illness.pdf.

Calder KJ, Pollitz K. (2006). *What Cancer Survivors Need to Know About Health Insurance*. Silver Spring, MD: National Coalition for Cancer Survivorship. Sixth Edition. Available at www.canceradvocacy.org.

The Cancer Legal Resource Center

866-THE-CLRC (866-843-2572)

Promotes the rights of people with disabilities, and the public interest in and awareness of those rights, by providing legal and related services.

National Cancer Institute (NCI) Cancer Information Service

800-4-CANCER (800-422-6237)

www.cancer.gov

Provides a list of organizations that provide financial assistance.

National Underinsured Resource Directory Booklet. (2010). Hampton, VA: Patient Advocate Foundation. Available at www.patientadvocate.org/pdf/pubs/NURDbooklet.pdf or 800-532-5274.

Needy Meds, Inc.

www.needymeds.org/

A clearinghouse for information about pharmaceutical assistance programs.

PACT+® Patient Assistance Program

800-996-6626

www.pactplusonline.com

A comprehensive program that includes reimbursement and patient assistance services to help take the challenge out of gaining access to medication for patients in need. The program also helps find alternative services and resources, including those relating to clothing, transportation, groceries, hospice, and other financial needs.

Partners for Prescription Assistance (PPA)

888-4PPA-NOW (888-477-2669)

www.pparx.org/

Helps qualifying patients who lack prescription coverage to access public and/or private programs.

Patient Advocate Foundation

800-532-5274

www.patientadvocate.org

Offers a help line with personalized assistance regarding many insurance, employment, and financial issues.

Social Security Administration

800-772-1213 or 800-325-0778 (TTY)

www.ssa.gov/

Administers federal disability programs that provide support to cancer survivors.

U.S. Department of Veterans Affairs (VA)

800-827-1000 or 800-829-4833 (TDD)

www.vba.va.gov/VBA

Provides information about VA medical health benefits and eligibility.

Caring for the Caregiver

Program length: 1 hour 17 minutes

Caring for the Caregiver was developed specifically to provide resources and support for cancer caregivers to help them address the issues they face on an ongoing basis. As a caregiver, it is easy to be overwhelmed by caring for a cancer survivor. An important point to remember is that you, as a caregiver, are *also* a survivor because you, too, are surviving the challenges, responsibilities, and life-changing effects of this disease and its treatment. Throughout this program, you will hear stories taken from real life and solutions that can provide you with the hope and options you need, while showing you ways to balance your own personal needs with those of the person you are caring for.

After listening to this Toolbox program, you will be better prepared to:

- Strengthen your skills and abilities while finding and using new resources
- Do a much better job of nurturing everyone involved—including yourself

Resources for Caring for the Caregiver

Blum D. (2008). *Caring for Your Loved One With Cancer*. New York, NY: CancerCare. Available at www.cancercare.org/pdf/booklets/ccc_caregiver.pdf or 800-813-HOPE (800-813-4673).

CancerCare

Caring for Someone You Love With Cancer. Free downloadable booklet from CancerCare.

www.cancercare.org/reading_room/

800-813-HOPE (800-813-4673)

Miller JE. (1996). *The Caregivers Book: Caring for Another: Caring for Yourself*. Minneapolis, MN: Augsburg Fortress.

Mintz S. (2007). *A Family Caregiver Speaks Up: It Doesn't Have to Be This Hard*. Herndon, VA: Capital Books, Inc.

National Cancer Institute (NCI)

800-4-CANCER

www.cancer.gov

Provides booklets and Internet information to help caregivers cope while caring for a loved one with cancer, as well as help someone with cancer cope with the illness.

NCI. *Taking Time: Support for People With Cancer and the People Who Care About Them*. (2009). Bethesda, MD: National Institutes of Health. NIH Publication #09-2059. Available at www.cancer.gov/cancertopics/takingtime.pdf or 800-4-CANCER (800-422-6237).

NCI. *When Someone You Love Is Being Treated for Cancer*. (2005). Bethesda, MD: National Institutes of Health. NIH Publication #05-5726. Available at www.cancer.gov/cancertopics/When-Someone-You-Love-Is-Treated/PDF or 800-4-CANCER (800-422-6237).

National Family Caregivers Association

800-896-3650

www.thefamilycaregiver.org

Educates, supports, empowers, and speaks up for people who care for loved ones with a chronic illness or disability.

Young Cancer Spouses

www.youngcancerspouses.org

Brings together young spouses of adults with cancer to share information, support, and experiences.

Living Beyond Cancer

Program length: 1 hour 48 minutes

Cancer survivorship is a day-to-day, ongoing process that begins with your diagnosis and continues through the rest of your life. *Living Beyond Cancer* discusses a number of important issues that are specific to life beyond the diagnosis and initial treatment of cancer.

Surviving cancer is more complicated than simply being sick or well, having cancer or being cancer-free. Instead, it is a continual process that is constantly changing. There may be times when the joy you feel about survival far outweighs any anxieties you may have. Then, there will be times when your fears and uncertainties seem to take over your life, and you wonder if you will ever feel normal again.

This program will introduce you to skills to help you adapt to your life after cancer. The goal is to help you, a cancer survivor, be as healthy as possible within your personal circumstances.

After listening to this Toolbox program, you will better understand:

- Common physical effects of cancer and its treatment, and what kind of medical records you need to keep to maintain a personal health history
- How to address concerns about sexuality and fertility
- How to support family relationships that may have changed during treatment
- The emotional aspects of cancer, including anxiety, depression, grief, and distress
- Health directives, wills and trusts, power of attorney, and financial planning
- How to live with hope while dealing with uncertainty

Resources for Living Beyond Cancer

Harpham WS. (2005). *Happiness in a Storm: Facing Illness and Embracing Life as a Healthy Survivor*. New York, NY: W. W. Norton & Company.

Journey Forward

877-NCCS-YES (877-622-7937)

www.journeyforward.org

Offers free software that enables healthcare professionals to create a treatment summary and post-treatment plan.

Keene N, Hobbie W, Ruccione K. (2006). *Childhood Cancer Survivors: A Practical Guide to Your Future*. Sebastopol, CA: O'Reilly & Associates, Inc. Second Edition.

Kydd S, Rowett D. (2006). *Intimacy After Cancer: A Woman's Guide*. Seattle, WA: Big Think Media.

Magee S, Scalzo K. (2007). *Picking Up the Pieces: Moving Forward After Surviving Cancer*. New Brunswick, NJ: Rutgers University Press.

NCI. *Facing Forward: Life After Cancer Treatment*. (2010). Bethesda, MD: National Institutes of Health. NIH Publication #10-2424. Available at www.cancer.gov/cancertopics/life-after-treatment.pdf.

NCI. *Facing Forward Series: Ways You Can Make a Difference in Cancer*. (2002). National Institutes of Health. NIH Publication #02-5088. Available at www.cancer.gov/cancertopics/make-a-difference/pdf.

Rosenbaum EH, Spiegel D, Fobair P, et al. (2007). *Everyone's Guide to Cancer Survivorship: A Roadmap for Better Health*. Kansas City, MO: Andrews McMeel Publishing, LLC.

Silver JK. (2006). *After Cancer Treatment: Heal Faster, Better, Stronger*. Baltimore, MD: Johns Hopkins Press Health Books.

Dying Well—The Final Stage of Survivorship

Program length: 1 hour 5 minutes

Although death is an inevitable part of life, few of us know just what to do or say or how to find the support we need when we are nearing the end of our lives and saying our final goodbyes. *Dying Well—The Final Stage of Survivorship* is an informative, supportive, and reassuring program designed to teach you more about your choices and resources and what to expect during this last stage of survival.

After listening to this Toolbox program, you and your loved ones will be better prepared to:

- Communicate with the members of your cancer care team, as well as family, friends, employers, and coworkers
- Manage hopes and expectations
- Deal with any anxiety or depression that may arise
- Make decisions about symptom management (including controlling pain) and continuing or stopping treatment
- Recognize what is happening during the dying process
- Make informed decisions about hospice/palliative care
- Manage grief

Resources for Dying Well—The Final Stage of Survivorship

Aging With Dignity and *Five Wishes*®

888-5-WISHES (888-594-7437)

www.agingwithdignity.org

Affirms and safeguards the human dignity of individuals as they age and promotes better care for those near the end of life. *Five Wishes* helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. It deals with all of a person's needs: medical, personal, emotional, and spiritual.

American Pain Foundation

888-615-PAIN (888-615-7246)

www.painfoundation.org

Dedicated to improving quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

Association of Oncology Social Work (AOSW)

215-599-6093

www.aosw.org

An organization of oncology social workers and others who specialize in helping cancer survivors and their families with the emotional and practical impact of cancer.

Bahti T. (2006). *Dying to Know: Straight Talk About Death and Dying*. Tucson, AZ: Pathways: Education & Consultation in End of Life Care. Available at www.pathwayseol.com/products.html.

CancerCare

800-813-HOPE (800-813-4673)

www.cancercare.org

A national organization that provides a toll-free counseling line and educational programs. Counseling and some materials are available in Spanish. All services are free of charge.

American Childhood Cancer Organization (formerly Candlelighters Childhood Cancer Foundation)

800-366-CCCCF (800-366-2223)

www.acco.org

Provides a network of support groups for children, parents, and caregivers.

Caring Connections

800-658-8898

caringinfo.org

Provides free resources and information to help people make decisions about end-of-life care and services before a crisis.

Children's Hospice and Palliative Care Coalition

831-763-3070

www.childrenshospice.org

Provides training and support to hospice teams to better meet the medical, emotional, and spiritual needs of the dying child and the family. Promotes policies and all-inclusive care programs that meet the complex medical, emotional, social, and practical needs of families who are experiencing great loss.

The Compassionate Friends

877-969-0010

www.compassionatefriends.org

Assists families toward the positive resolution of grief following the death of a child of any age and provides information to help others be supportive.

Elisabeth Kübler-Ross Foundation

www.ekrfoundation.org

Provides information and resources related to end-of-life care and for those who are grieving.

Good Grief

908-522-1999

www.good-grief.org

Provides direct services for children and adults coping with loss due to death.

Group Loop

888-793-WELL (888-793-9355)

www.grouploop.org

Provides online support for teens with cancer and their parents.

Harwell A. (2000). *Ready to Live: Prepared to Die—A Provocative Guide to the Rest of Your Life*. Wheaton, IL: Shaw Publishing.

Hospice and Palliative Nurses Foundation

412-787-9301

www.hpnf.org

Hospice Foundation of America

800-854-3402

www.hospicefoundation.org

Provides general information about hospices and will assist you in locating a hospice near you.

National Association of Social Workers (NASW)

202-408-8600

www.socialworkers.org

www.helpstartshere.org – Offers many resources, including “Understanding End of Life Care”

www.naswwebed.org – Provides online courses on cancer, cancer caregiving, and end-of-life care for consumers and professionals.

www.helppro.com/nasw/Default.aspx – Offers assistance in finding licensed social workers through the National Social Worker Finder.

National Center for Grieving Children & Families (The Dougy Center)

866-775-5683

www.grievingchild.org

Provides support and training to individuals and organizations seeking to assist children in grief.

National Hospice and Palliative Care Organization

800-658-8898

www.nhpco.org

Offers assistance in finding a hospice; also provides consumer-oriented materials. Printed materials can be ordered by calling the number above.

On Our Own Terms: Moyers on Dying

800-257-5126

www.pbs.org/wnet/onourown/terms

Video tapes of this 4-part, 6-hour PBS series on end-of-life issues may be ordered by calling Films of the Humanities at the number above.

Pathways: Education & Consultation in End of Life Care

520-400-0274

www.pathwayseol.com

Provides resources designed to help improve end-of-life care.

Planet Cancer

www.planetcancer.org

A LIVESTRONG initiative to create a community of young adults with cancer in their 20s and 30s.

The website includes blogs, resources, and “cancertainment.”

VI. Other Important Information

Treatment Guidelines

The National Comprehensive Cancer Network (NCCN) and the American Cancer Society worked together to develop the *NCCN Clinical Practice Guidelines in Oncology*™, which are available to clinicians and nonclinicians at www.nccn.org.

NCCN also offers patient-focused summaries based on these guidelines through a consumer website, www.nccn.com. The online summaries help patients understand treatment options for their disease and prepare them to talk to their doctors about the therapies that may be right for them. In addition to offering patient-friendly summaries based on the NCCN guidelines, the consumer website provides information on living with cancer, paying for cancer treatment, cancer survivorship, and other topics.

Decision-Making Tools

Many organizations that focus on specific types of cancer have resources to help with making decisions. The American Cancer Society also has an online treatment decision-making tool for many different types of cancer that can help you make an informed decision about your treatment and pinpoint topics you should discuss with your doctor. The Treatment Decision Tool is available at www.cancer.org.

Health Insurance and Related Laws

COBRA, the **Consolidated Omnibus Budget Reconciliation Act**, gives some workers the right to keep their health insurance coverage for a limited period of time after they leave their jobs. The booklet, *An Employee's Guide to Health Benefits Under COBRA*, contains detailed information about COBRA and is available at www.dol.gov/ebsa/publications/cobraemployee.html or 866-444-EBSA (866-444-3272) toll free.

The **Americans with Disabilities Act**, often called the “ADA,” was passed in 1990 and protects workers from job discrimination based on disability or disease. To file a complaint under the ADA, call the Equal Employment Opportunity Commission (EEOC) toll free at 800-669-4000 or 800-669-6820 (TTY) to obtain the location of your regional EEOC office.

ERISA, the federal **Employee Retirement Income Security Act**, is the nation's major pension law and provides rights and protections for private pension and health benefit plan participants and their beneficiaries. ERISA prohibits an employer from discriminating against an employee for the purposes of preventing the employee from collecting benefits under an employee benefit plan.

The **Family and Medical Leave Act** requires an employer to provide an employee with the same or a similar job in the event the employee needs to take an unpaid leave of absence. This law lets eligible employees take up to 12 weeks of leave for certain family or medical reasons. Employers with 50 or more employees within 75 miles of the workplace are covered by the Act. To file a complaint under the Family and Medical Leave Act, contact the Employment Standards Administration, Wage and Hour Division, of the United States Department of Labor. A regional office will be listed in your local telephone book under *United States Government*.

The **Health Insurance Portability and Accountability Act (HIPAA)** was passed by Congress in 1996. This legislation protects many workers from discrimination based on preexisting medical conditions and other health-related factors. This law protects employees from losing their insurance when they change jobs or move to a different state. The HIPAA helps some employees keep their health insurance when they change jobs. It does not prevent increases in premiums associated with a new group plan or when the insured person moves to a new location.

Additional Health Insurance and Financial Resources

It's Your Choice: Are Medicare HMOs Right for You? This 30-page booklet was written by Consumer Action, with assistance from the Gray Panthers and the National Consumers League. It advises people currently on Medicare about changes taking place in Medicare and what they mean. Available online in English and Spanish from Consumer Action at www.consumer-action.org or 415-777-9635.

The Managed Care Answer Guide. This 32-page booklet, covering the terminology of managed care, is a consumer's guide to selecting an insurance plan and understanding the provisions of your plan. You may download a free copy at www.patientadvocate.org/pdf/pubs/mc_answer-guide.pdf.

Protect Your Pension: A Quick Reference Guide. You may order a free copy of this publication with information on safeguarding your pension plan via the following phone number or website:

U.S. Department of Labor
Employee Benefits Security Administration
866-444-EBSA (866-444-3272)
www.dol.gov/ebsa

What Cancer Survivors Need to Know About Health Insurance. This National Coalition for Cancer Survivorship booklet includes new information about the Health Insurance Portability and Accountability Act (HIPAA). Available at www.canceradvocacy.org or 877-NCCS-YES (877-622-7937).

Types of Cancer Treatment Centers/Second Opinions

Desirable cancer treatment facilities can be found in many different settings, ranging from doctors' offices to hospital-based outpatient clinics to community cancer centers to the National Cancer Institute—designated and comprehensive cancer centers that do cancer research and provide clinical care and services to individuals with cancer. To find these designated cancer centers and learn more about them, use the National Cancer Institute's website, cancercenters.cancer.gov.

There is also an organization, the R. A. Bloch Cancer Foundation, that maintains a list of places that offer multidisciplinary second opinions for cancer patients. The list is arranged by state and has a contact name and phone number for each cancer center. You can access this list at blohcancer.org/2009/03/multidisciplinary-second-opinion-centers/ or by calling the Bloch Foundation's toll-free cancer hotline at 800-433-0464.

Clinical Trials

The clinical trial process for potential new treatment methods involves 4 phases. In phase 1 trials, the goal is to discover harmful side effects. Researchers also try to learn the best way to give new treatments and decide the correct dose. Most phase 1 trials include a small number of people: usually less than 50 participants. Phase 2 trials usually include fewer than 100 people and are designed to test whether the new treatment is effective against one type of cancer. If the phase 2 trial has good results, the treatment method can be tested in phase 3 trials, which compare the new treatment method to the best treatment that is now in use against that one type of cancer. Phase 3 trials can enroll hundreds and even thousands of people, who will get either the new treatment or the best existing or standard form of treatment. After new treatment methods have been proven to have benefits over the best standard treatment, the new treatment can be approved by the U.S. Food and Drug Administration (FDA) for general use. Usually, newly FDA-approved treatments are followed in phase 4 trials, also called postmarketing trials, in which problems or concerns with the drug are reported to the FDA and the drug undergoes more testing to assure its effects and overall safety.

Resources

You can get information about clinical trials from members of your cancer care team. They may have individuals already taking part in various trials. Information on cancer trials is also available from the National Cancer Institute (NCI) website (www.cancer.gov). Information about clinical trials is also available toll-free from NCI's telephone-based Cancer Information Service (CIS) at 800-4-CANCER (800-422- 6237).

Several websites offer clinical trial matching services. The Coalition of Cancer Cooperative Groups (CCCCG) has a website (www.cancertrialshelp.org) that offers the "Patient and Caregiver Toolkit"—a package of practical information and publications you can use to learn about cancer clinical trials. In addition, the CCCCg offers a search engine or database of cancer-related clinical trials, available at www.cancertrialshelp.org/trialcheck. The American Cancer Society has information on clinical trials as well, including trial-matching services and laws pertaining to trials, available at www.cancer.org/Treatment/TreatmentsandSideEffects/ClinicalTrials/index.

Questions to Ask

The CCCCg suggests asking your doctor these 10 questions if you are thinking of taking part in a clinical trial:

1. Why would this trial be important for me? What is the aim of the study?
2. What are the potential risks and benefits to me compared to other treatment options I have?
3. What are the eligibility requirements?
4. Who will monitor my care and safety?
5. What are the trial's tests and treatments? Will I need to be in the hospital, and if so, how often and for how long?
6. How do the possible side effects of the study treatment compare to side effects of the standard treatment option?
7. What support will be there for me and my caregivers during the trial? Can I talk to someone if I have questions?
8. Will my insurance, Medicaid, Medicare, or managed care plan cover costs of the trial? Who will help me answer these coverage questions?
9. What are my responsibilities and out-of-pocket costs?
10. What is the long-term follow-up care?

Connecting With Others and Finding Meaning

Many people want to find meaning in their experience with cancer. One way to make sense of what has happened is by helping others and giving back. This might be done by mentoring newly diagnosed survivors. Or participating in support groups. Or raising money for a cancer organization. Or “advocating” (speaking out for) improved care, treatment, and research.

Studies show that helping others may lead to better mental health. It can help people feel empowered. It offers people a positive focus for their energies. And, it may help people find friendship and support among fellow survivors.

The Basic Skills in the *Cancer Survival Toolbox* can be used to help others. For example:

- **Communicating:** Speak at a local survivorship conference about your experience
- **Finding Information:** Gather resources you have found useful and share them with other survivors
- **Making Decisions:** Help a recently diagnosed friend list the pros and cons of different treatment options
- **Solving Problems:** Identify a survivorship need in your community and find a way to fill that need
- **Negotiating:** Sit on a hospital panel that makes decisions about funding or research
- **Standing Up for Your Rights:** Educate the public by talking about your experiences at community events such as town hall meetings or panel discussions

Other Ways to Get Involved

NCCS can help you find ways to help other survivors. Contact us at advocacy@canceradvocacy.org or 877-NCCS-YES (877-622-7937).

A few suggestions:

- Keep the *Cancer Survival Toolbox* on hand to give to other survivors. Order copies by calling 877-NCCS-YES, visiting www.canceradvocacy.org, or downloading through iTunes
- NCCS has a tip card that highlights the Basic Skills and lists resources and outlets for getting involved in advocacy. Ask for a copy
- NCCS also has trainings on our website (www.canceradvocacy.org). You can learn more about being a cancer advocate. You can find “nuts and bolts” guidance on different advocacy activities. And, you can learn more about how to share your experiences with others

Facing Forward: Making a Difference in Cancer offers advice and direction for getting involved in advocacy. Visit www.cancer.gov or call 800-4-CANCER (800-422-6237) for a free copy.

Some resources for connecting to others with the same type of cancer:

- The National Cancer Institute’s Cancer Information Service
- Nongovernmental organizations like the American Cancer Society, Imerman Angels, and the R. A. Block Cancer Foundation
- Advocacy organizations that focus on a specific type of cancer connect cancer survivors with others who have been more recently diagnosed. Check with a group that offers services to people with your type of cancer. Links to these groups are listed on the NCCS website (www.canceradvocacy.org).

Examples are:

- Leukemia & Lymphoma Society
- C3 Colorectal Cancer Coalition
- National Breast Cancer Coalition
- Us TOO International, Inc.

VII. Survivorship Tools

Distress Thermometer

The emotional distress that cancer causes can take many forms. Anxiety, anger, depression, and frustration are all quite common. Cancer specialists use the Distress Thermometer to help them measure the emotional impact of cancer on survivors. We have included a copy here for your reference. If you are experiencing emotional distress from your cancer, it is very important to know that help is available, and to go get the help you need. The Distress Thermometer may help you describe the way you are feeling to your healthcare team.

From the *NCCN Clinical Practice Guidelines in Oncology™: Distress Management* (V.1.2011). Jenkintown, PA: National Comprehensive Cancer Network; January 2010. To view the most recent and complete version of the guideline, visit www.nccn.org.

Keeping Track of Your Treatment Record

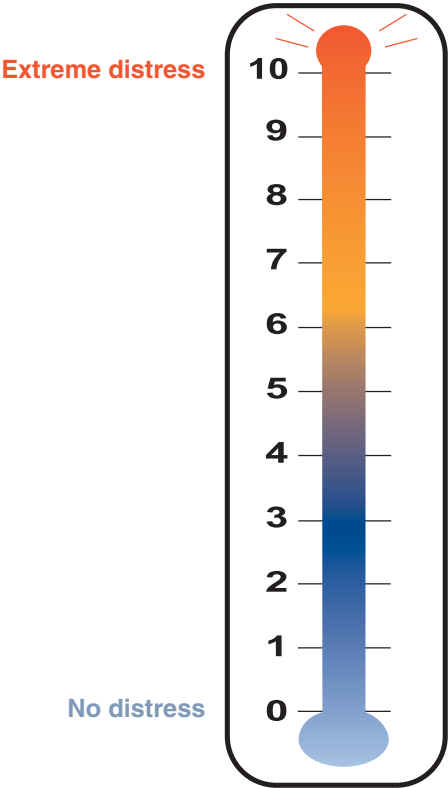
Journey Forward is a program that helps cancer survivors collaborate with their physicians to create treatment summaries and follow-up care plans that provide clear steps for care and monitoring after cancer treatment. The program offers a Survivorship Toolkit for both patients and professionals. It also provides the *Survivorship Care Plan Builder*, free software that helps you create a custom-made care plan, as well as an electronic *Medical History Builder*. Both are available at www.journeyforward.org.

NCCN®

Practice Guidelines
in Oncology – V.1.2011

Screening tools for measuring distress

Instructions: First, please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



Distress Management

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

Yes	No	<u>Practical Problems</u>	Yes	No	<u>Physical Problems</u>
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
		<u>Family Problems</u>	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
		<u>Emotional Problems</u>	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	<u>Spiritual/Religious Concerns</u>	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
			<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

Other Problems: _____

VIII. Resources for Cancer Survivors

National Coalition for Cancer Survivorship (NCCS) Resources

The following resources are available from NCCS at www.canceradvocacy.org or 877-NCCS-YES (877-622-7937).

Calder KJ, Pollitz K. (2006). *What Cancer Survivors Need to Know About Health Insurance*. Silver Spring, MD: National Coalition for Cancer Survivorship. Sixth Edition. Available in English and Spanish.

Clark EJ (ed). (2010). *Teamwork: The Cancer Patient's Guide to Talking with Your Doctor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fifth Edition. Available in English and Spanish.

Clark EJ. (2008). *You Have the Right to Be Hopeful*. Silver Spring, MD: National Coalition for Cancer Survivorship. Fourth Edition. Available in English and Spanish.

Hoffman B (ed). (2008). *Working It Out: Your Employment Rights as a Cancer Survivor*. Silver Spring, MD: National Coalition for Cancer Survivorship. Ninth Edition. Available in English and Spanish.

Journey Forward. A free software program that helps cancer survivors collaborate with their physicians to create treatment summaries and plans for follow-up care that provide clear steps for care and monitoring after cancer treatment. Available at www.journeyforward.org or e-mail info@journeyforward.org.

Scherr SL. (2009). *Self-Advocacy: A Cancer Survivor's Handbook*. Silver Spring, MD: National Coalition for Cancer Survivorship. Second Edition. Available in English.

National Cancer Institute (NCI) Resources

The following publications are available from NCI at 800-4-CANCER (800-422-6237) or at the individual websites listed below.

NCI. (2010). *Facing Forward: Life After Cancer Treatment*. Bethesda, MD: National Institutes of Health. NIH Publication #10-2424. Available at www.cancer.gov/cancertopics/life-after-treatment.pdf.

NCI. (2002). *Facing Forward: Ways You Can Make a Difference in Cancer*. National Institutes of Health. NIH Publication #02-5088. Available at www.cancer.gov/cancertopics/make-a-difference/pdf.

NCI. (2009). *Taking Time: Support for People With Cancer and the People Who Care About Them*. Bethesda, MD: National Institutes of Health. NIH Publication #09-2059. Available at www.cancer.gov/cancertopics/takingtime.pdf.

NCI. (2005). *When Someone You Love Is Being Treated for Cancer*. Bethesda, MD: National Institutes of Health. NIH Publication #05-5726. Available at www.cancer.gov/cancertopics/When-Someone-You-Love-Is-Treated/PDF.

General Information

Ackermann A, Ackermann A. (2002). *Our Mom Has Cancer*. Atlanta, GA: American Cancer Society.

American Cancer Society/National Endowment for Financial Education. (2008). *Taking Charge of Money Matters*. Atlanta, GA: ACS/NEFE.

This series of booklets (in PDF format) covers a wide range of financial topics you may need to know about throughout your cancer experience. Available at www.cancer.org/Treatment/FindingandPayingforTreatment/UnderstandingFinancialandLegalMatters/TakingChargeofMoneyMatters/index.

Bahti T. (2006). *Dying to Know: Straight Talk About Death and Dying*. Tucson, AZ: Pathways: Education & Consultation in End of Life Care. Available at www.pathwayseol.com/products.html.

Blum D. (2008). *Caring for Your Loved One With Cancer*. New York, NY: CancerCare. Available at www.cancercare.org/pdf/booklets/ccc_caregiver.pdf.

Clark EJ, Stovall E. (1996). Advocacy: The cornerstone of cancer survivorship. *Cancer Practice*, vol 4, pgs 239-244.

Coping® With Cancer Magazine
615-790-2400
copingmag.com/cwc/index.php

CURE: Cancer Updates, Research, & Education Magazine
800-210-CURE (800-210-2873)
www.curetoday.com

Donaldson MC, Frohnmayer D (foreword). (2007). *Negotiating for Dummies*. Hoboken, NJ: Wiley Publishing, Inc.

Feuerstein M, Findley P. (2006). *The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer*. New York, NY: Marlowe & Company.

Filigenszi, C. (2009). *Let My Colors Out*. Atlanta, GA: American Cancer Society.

Galsky M. (2009). *Everything You Need to Know about Cancer*. Sudbury, MA: Bartlett Publishing, LLC.

Gruman J. (2007). *After Shock: What to Do When the Doctor Gives You—or Someone You Love—A Devastating Diagnosis*. New York, NY: Walker and Company.

Harpham WS. (2003). *Diagnosis: Cancer. Your Guide Through the First Few Months of Healthy Survivorship*. New York, NY: W. W. Norton & Company. Third Edition.

Harpham WS. (2005). *Happiness in a Storm: Facing Illness and Embracing Life as a Healthy Survivor*. New York, NY: W. W. Norton & Company.

Harpham WS. (2004). *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York, NY: HarperCollins.

Harwell A. (2000). *Ready to Live: Prepared to Die—A Provocative Guide to the Rest of Your Life*. Wheaton, IL: Shaw Publishing.

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IX. Alphabetical List of Support Organizations and Other Resources

Important phone numbers and Internet addresses mentioned throughout the entire Toolbox audio program are listed below. For additional resources, please visit the Toolbox website at www.canceradvocacy.org/toolbox.

Use this key to help you identify which organizations/resources may be of most use to you at this time.

- Clinical Trial Information
- Financial Issues/Legal Issues/Employment/Health Insurance
- ◆ Resources for All Cancer Types
- * Pain and Palliative Care
- ◆ Sexuality/Fertility
- ✚ Young Adults
- Older Persons
- ✚ Caregivers
- Underserved/Minorities/Disabilities
- ✚ Support Groups/One-on-One Support/Staying Connected/Retreats

AARP (American Association of Retired Persons) ■ ○ ✚ ✚

888-OUR-AARP (888-687-2277)

www.aarp.org/families/caregiving

Provides various resources on issues of caregiving, such as long-term financing, home care, housing options, video and written resources, and an online weekly caregiver support group.

Aging With Dignity and Five Wishes® ○

888-5-WISHES (888-594-7437)

www.agingwithdignity.org

Affirms and safeguards the human dignity of individuals as they age and promotes better care for those near the end of life. *Five Wishes* helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. It deals with all of a person's needs: medical, personal, emotional, and spiritual.

American Association for Geriatric Psychiatry ○ ✚

301-654-7850

www.aagpgpa.org

Provides referrals for geriatric psychiatrists. Also offers written materials for patients, family members, and caregivers.

American Association of Sexuality Educators, Counselors, and Therapists ◆

202-449-1099

www.aasect.org

Devoted to the promotion of sexual health by the development and advancement of the fields of sex therapy, counseling, and education. Their website can help you locate a sexuality educator, counselor, or therapist in your area.

American Cancer Society ● ■ ◆ ✱ ◆ ✚ ○ ✚ □ ✚

800-ACS-2345 (800-227-2345)

www.cancer.org

Provides written information about cancer, cancer research, and treatment options. Call to locate a chapter near you and learn about what programs and resources are being offered, including the Patient Navigator Program.

American Childhood Cancer Organization ● ■ ◆ ✚ ✚ (formerly Candlelighters Childhood Cancer Foundation)

800-366-CCCC (800-366-2223)

www.acco.org

Provides a network of support groups for children, parents, and caregivers.

American Chronic Pain Association ✱

800-533-3231

www.theacpa.org

Provides support for persons dealing with chronic pain. There are more than 800 chapters, and you may find the one closest to you by calling their central number.

American Pain Foundation ✱

888-615-PAIN (888-615-7246)

www.painfoundation.org

Dedicated to improving quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

American Pain Society ✱

847-375-4715

www.ampainsoc.org

Provides a directory of more than 500 pain treatment centers in the United States.

America's Health Insurance Plans ■

202-778- 3200

www.ahip.org

A national association representing nearly 1,300 member companies providing health insurance coverage. Their website provides consumer information about private insurance, managed care, getting coverage, and answers to frequently asked questions. Access health plan offerings on their comprehensive, national directory (locator).

Association of Oncology Social Work (AOSW) ■ ◆ ✱ ✚ ○ ✚ □ ✚

215-599-6093

www.aosw.org

An organization of oncology social workers and others who specialize in helping cancer survivors and their families with the emotional and practical impact of cancer.

BBB Wise Giving Alliance ◆

703-276-0100

www.bbb.org/us/charity/

A service of the Better Business Bureau, offering information on legitimate charities and causes.

Blogger.com ✚

www.blogger.com

A way to share your thoughts, photos, and more with your friends and the world.

C3: Colorectal Cancer Coalition ● ✚

877-4CRC-111 (877-427-2111) or 703-548-1225

www.fightcolorectalcancer.org

A national nonprofit advocacy organization whose mission is to win the fight against colorectal cancer through research, empowerment, and access. Provides information about colorectal cancer and clinical trials.

CancerCare ■ ◆ ✱ ○ ✱

800-813-HOPE (800-813-4673)

www.cancercares.org

A national organization that provides a toll-free counseling line and educational programs. Counseling and some materials are available in Spanish. All services are free of charge.

Cancer Legal Resource Center ■

866-THE-CLRC (866-843-2572)

www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm

Promotes the rights of people with disabilities, and the public interest in and awareness of those rights, by providing legal and related services.

Cancer.Net ● ■ ◆ ✱ ◆ ✱ ○ ✱

888-651-3038

www.cancer.net

A patient education website from the American Society of Clinical Oncology (ASCO) that provides information on more than 50 types of cancer and their treatments, clinical trials, side effects, and coping. Also includes live chats, message boards, and links to support groups.

Cancer Support Community (includes The Wellness Community and Gilda's Club)

● ■ ◆ ✱ ✱ ✱

888-793-WELL (888-793-9355)

www.cancersupportcommunity.org

www.thewellnesscommunity.org

A national nonprofit organization dedicated to providing free emotional support, education, and hope for people with cancer and their loved ones. Through participation in professionally led support groups, educational workshops, and mind/body programs utilizing the Patient Active Concept, people affected by cancer can learn vital skills to regain control, reduce feelings of isolation, and restore hope—regardless of the stage of disease. All programs are free of charge.

Caregiver Media Group ● ■ ◆ ✱ ✱

800-829-2734

www.caregiver.com

Provides an online newsletter, workshops, audiotapes, and information on caregivers and the work force, caregiver tips, and other topics.

CaringBridge ✱

651-789-2300

www.caringbridge.org/

Offers free, personalized websites that connect family and friends during a serious health event.

Caring Connections ✱

800-658-8898 or 877-658-8896 (multilingual)

caringinfo.org

Provides free resources and information to help people make decisions about end-of-life care and services before a crisis.

Children's Hospice and Palliative Care Coalition ✱

831-763-3070

www.childrenshospice.org

Provides training and support to hospice teams to better meet the medical, emotional, and spiritual needs of the dying child and the family. Promotes policies and all-inclusive care programs that meet the complex medical, emotional, social, and practical needs of families who are experiencing great loss.

Circle of Sharing™ ✱

circleofsharing.cancer.org/

An American Cancer Society resource that helps cancer patients and their caregivers get personalized information about the disease, and share that information with family and friends.

The Compassionate Friends ✱

877-969-0010

www.compassionatefriends.org

Assists families toward the positive resolution of grief following the death of a child of any age and provides information to help others be supportive.

Consumer Action ■ ○ □

415-777-9635

www.consumer-action.org

Provides a downloadable 30-page booklet, *It's Your Choice: Are Medicare HMOs Right for You?*, written with assistance from the Gray Panthers and the National Consumers League. Available in English and Spanish, this brochure advises people currently on Medicare about changes taking place in Medicare and what they mean.

Council of Better Business Bureaus ◆

703-276-0100

www.bbb.org/us

Can be used to learn whether a business is legitimate, before paying for a service or merchandise.

CURE: Cancer Updates, Research, & Education Magazine ● ■ ◆ ◆

800-210-CURE (800-210-2873)

www.curetoday.com

Eldercare Locator ■ ◆ ○

800-677-1116

www.eldercare.gov

A nationwide, directory-assistance service designed to help older persons and caregivers locate local support resources. Links you with state and local area agencies on aging, where you can get information about services such as transportation, meals, home care, housing alternatives, legal issues, and social activities.

Elisabeth Kübler-Ross Foundation ✱

www.ekrfoundation.org

Provides information and resources related to end-of-life care and for those who are grieving.

Family Caregiver Alliance ✱

800-445-8106

www.caregiver.org

A clearinghouse that covers current medical, social, public policy, and caregiving issues related to brain impairments in adults, including brain tumors. Information is also available in Spanish and Chinese.

Fertile Hope ● ■ ◆ ◆ ✱ ✱

866-965-7205

www.fertilehope.org

Dedicated to providing reproductive information, support, and hope to cancer patients whose medical treatments present the risk of infertility. Focuses on research, awareness, education, financial assistance, and support.

Gerontological Society of America ○

202-842-1275

www.geron.org

An organization for professionals in the field of aging that focuses on promoting the scientific study of aging. Provides reports, bibliographic searches (\$5 per keyword), publications, and a list of online resources useful to older persons with cancer and their caregivers.

Good Grief ✱

www.good-grief.org

Provides direct services for children and adults coping with loss due to death.

Group Loop ◆ ✱ ✱

888-793-WELL

www.grouploop.org

Website from the Cancer Support Community provides online support for teens with cancer and their parents.

HealthGrades ◆

www.healthgrades.com/

A leading independent nonprofit that rates physicians, hospitals, and nursing homes.

Health Insurance Counseling and Advocacy Program (HICAP) ■ ○ □

800-434-0222

www.aging.ca.gov/information_on/hicap.asp

A Medicare assistance program for the elderly and disabled. HICAP helps people learn about Medicare benefits including Medicare HMOs, long-term care, Medicare supplemental or long-term care insurance, and other important changes in Medicare.

Hospice Foundation of America ✱ ○ ✱ ✱

800-854-3402

www.hospicefoundation.org

Provides general information about hospices and will assist you in locating a hospice near you. Also available from their website is *The Dying Process: A Guide for Caregivers*, a free booklet that discusses both the physical symptoms of dying and the psychological issues that accompany the dying process.

Imerman Angels ✱

877-274-5529

www.imermanangels.org/

Carefully matches and individually pairs a person touched by cancer with a survivor of the same type of cancer.

Impotence Specialists.com ◆

www.impotencespecialists.com

This website can help you find a physician in your area and offers information about treatment options.

Intercultural Cancer Council (ICC) □

713-798-4614

www.iccnetwork.org

Works to eliminate the unequal burden of cancer in racial and ethnic minorities and medically underserved populations. Offers a wide variety of educational programs.

Journey Forward ◆

877-NCCS-YES (877-622-7937)

www.journeyforward.org

Offers free software that enables healthcare professionals to create a treatment summary and post-treatment plan.

Lance Armstrong Foundation/LIVESTRONG ◆ ✚

866-673-7205

www.livestrong.org

Seeks to promote the optimal physical, psychological, and social recovery and care of cancer survivors and their loved ones. The site features survivors discussing their experiences as well as links to more information.

Leukemia & Lymphoma Society (LLS) ● ■ ◆ ✚

800-955-4572

www.leukemia.org/hm_lls

This organization provides support services, including local support groups and financial assistance to persons with leukemia, lymphoma, and multiple myeloma. Information about LLS resources is available in English, Spanish, Portuguese, and French.

Life Insurance Settlement Association ■

407-894-3797

www.thevoiceoftheindustry.com

Provides a list of viatical companies that will buy your life insurance policies under certain conditions.

Medicare ■ □

800-MEDICARE (800-633-4227) or 877-486-2048 (TTY/TDD)

www.medicare.gov

U.S. government agency that provides various services (in English and Spanish), including publications on Medicare health plans and Medicare managed care choices. Some publications are also available in Braille or audio format for the visually impaired.

MyLifeLine ✚

www.MyLifeLine.org

Offers free, customizable websites to empower cancer patients and caregivers to build an online community of friends and family.

National Academy of Elder Law Attorneys ■ ○

703-942-5711

www.naela.com

Offers *Questions and Answers When Looking for an Elder Law Attorney*, a pamphlet that covers issues such as where to find an attorney, what questions to ask, how to discuss fees, and more, available either online at www.naela.org/About_QandA.aspx or by sending a stamped self-addressed business-sized envelope to: NAELA Q & A, 1577 Spring Hill Road, Suite 220, Vienna, VA 22182.

National Association of Community Health Centers ■ □

301-347-0400

www.nachc.com

Provides a listing of local nonprofit, community-owned healthcare programs serving low income and medically underserved urban and rural communities.

National Association of Social Workers (NASW) ◆ ✚

202-408-8600

www.socialworkers.org

www.helpstartshere.org

NASW, the largest membership association of social workers nationwide, provides a consumer website with information and advice regarding health, mental health, cancer, and other illnesses, as well as a way to find a social worker near you through their National Social Worker Finder, available at www.helppro.com/nasw/Default.aspx.

National Breast Cancer Coalition ● ✚

800-622-2838 or 202-296-7477

www.stopbreastcancer.org

Informs, trains, and directs patients and others in effective advocacy efforts. Seeks to increase nationwide awareness of breast cancer public policy by participating in legislative, scientific, and regulatory decisions; promoting positive media coverage; and actively working to raise public awareness.

National Cancer Institute (NCI) ● ■ ◆ ✱ ◆ ✚ ○ ✚ □

800-4-CANCER (800-422-6237)

www.cancer.gov

Offers many educational resources for cancer survivors, including the Cancer Information Service (CIS), a network of regional offices providing easy-to-understand information in English and Spanish on cancer treatment, research, and local cancer-related services and community resources, along with a list of organizations that provide financial assistance. The NCI website features information about clinical trials as well as these publications: *Facing Forward: Life After Cancer Treatment*; *Facing Forward: Ways You Can Make a Difference in Cancer*; *Taking Time: Support for People With Cancer and the People Who Care About Them*; *When Someone You Love Is Being Treated for Cancer*; and *When Somebody in Your Family Has Cancer*.

National Coalition for Cancer Survivorship (NCCS) ■ ◆ ◆ ○ ✚ □

877-NCCS-YES (877-622-7937)

www.canceradvocacy.org

Advocates for quality cancer care for all Americans and provides tools that empower people affected by cancer to advocate for themselves. Founded by and for cancer survivors in 1987, NCCS created the widely accepted definition of survivorship and considers someone a cancer survivor from the time of diagnosis through the balance of life. Its free publications and resources include the award-winning *Cancer Survival Toolbox*, a self-learning audio program created by leading cancer organizations to help people develop essential skills to meet the challenges of their illness.

National Comprehensive Cancer Network ◆

215-690-0300

www.nccn.com/

Provides treatment summaries for people with cancer.

National Family Caregivers Association ◆ ✚ ✚

800-896-3650

www.nfcacares.org

Advocates on behalf of caregivers. Services include education, information, support, public awareness, and advocacy.

National Hospice and Palliative Care Organization ✱ ○ □

800-658-8898

www.nhpco.org

Offers assistance in finding a hospice; also provides consumer-oriented materials. Printed materials can be ordered by calling the number above.

NCI Physician Data Query (PDQ®) ● ◆

800-4-CANCER (800-422-6237)

www.cancer.gov/cancertopics/PDQ

With sections for patients as well as physicians, this comprehensive cancer database contains summaries on a range of cancer topics; a registry of cancer clinical trials; and a directory of professionals who provide genetics services. PDQ also contains the NCI Dictionary of Cancer Terms and the NCI Drug Dictionary.

Needy Meds, Inc. ■

www.needymeds.org

A clearinghouse for information about getting medications from pharmaceutical companies. There is no charge for the service.

Office of Minority Health Resource Center □

800-444-6472

www.omhrc.gov

Provides health information regarding Native American, Alaska Native, African American, Asian American, Native Hawaiian/Pacific Islander, and Hispanic/Latino populations.

OncoLink ● ■ ◆ ✱ ◆ ✚ ✚

www.oncolink.upenn.edu

A website managed by the Abramson Cancer Center of the University of Pennsylvania that provides a wide range of cancer-related information. Also includes information on clinical trials, reimbursement assistance programs, and a caregiver education course.

Oncology Nursing Society ◆

866-257-4ONS (866-257-4667)

www.ons.org

A national organization composed of more than 37,000 registered nurses and other healthcare providers who work with persons who have cancer. Their website has a special section for patient information and educational resources.

PACT+® Patient Assistance Program ■

800-996-6626

www.pactplusonline.com

A comprehensive program that includes reimbursement and patient assistance services to help take the challenge out of gaining access to medication for patients in need. The program also helps find alternative services and resources, including those relating to clothing, transportation, groceries, hospice, and other financial needs.

Pancreatic Cancer Action Network (PanCAN) ✚

877-272-6226

www.pancan.org

A nationwide network that helps connect pancreatic cancer survivors with others who have been more recently diagnosed.

Partnership for Prescription Assistance (PPA) ■

888-4PPA-NOW (888-477-2669)

www.pparx.org

Helps qualifying patients who lack prescription coverage to access public and/or private programs. Information is available in both English and Spanish.

Pathways: Education & Consultation in End of Life Care ◆ ✚

520-400-0274

www.pathwayseol.com

Provides resources designed to help improve end-of-life care.

Patient Advocate Foundation ■ ◆

800-532-5274

www.patientadvocate.org

Offers *The Managed Care Answer Guide*. This 32-page booklet, covering the terminology of managed care, is a consumer's guide to selecting an insurance plan and understanding the provisions of your plan. You may download a free copy at www.patientadvocate.org/pdf/pubs/mc_answer-guide.pdf.

Planet Cancer ✚

www.planetcancer.org

A LIVESTRONG initiative to create a community of young adults with cancer in their 20s and 30s. The website includes blogs, resources, and "cancertainment."

R. A. Bloch Cancer Foundation ◆

800-433-0464

www.blochcancer.org

A nonprofit organization that provides a list of multidisciplinary second opinion services.

Social Security Administration ■

800-772-1213 or 800-325-0778 (TTY)

www.ssa.gov

An agency of the federal government that manages Social Security, Supplemental Security Income, Medicare, and parts of Medicaid. Information is available in English, Spanish, and many other languages.

Susan G. Komen for the Cure ✚

877-GO-KOMEN (877-465-6636)

www5.komen.org

This organization provides information in English and Spanish about breast health and breast cancer research as well as a toll-free "Helpline" that is staffed by trained volunteers.

Survivors' Retreat ✚

www.survivorsretreat.com/index.html

Maintains a list of retreats, spa opportunities, labyrinths, and conferences for cancer survivors.

Ulman Cancer Fund for Young Adults ✚ ✚

888-393-3863 or 410-964-0202

www.ulmanfund.org

A leading voice in the young adult cancer movement, working at a grassroots level to support, educate, connect, and empower young adult cancer survivors. Offers one-on-one support and navigation services.

U.S. Department of Veterans Affairs ■ ✚ ✚

800-827-1000

www.va.gov

Veterans can consult with a VA benefits counselor at any VA Medical Center, or call the Department of Federal Benefits.

Us TOO International, Inc. ✚

800-80-US-TOO (800-808-7866)

www.ustoo.com

This international network of chapters provides support and services to men with prostate cancer and their loved ones.

Well Spouse Association + ✿

800-838-0879

www.wellspouse.org

Provides a quarterly newsletter, pamphlets, mutual aid support groups in many areas, letter-writing support groups, an annual conference, and regional and weekend meetings around the country for caregivers.

Y-ME National Breast Cancer Organization ● ✿

800-221-2141 or 312-986-8338

www.networkofstrength.org

Provides immediate emotional relief to anyone affected by breast cancer. This organization's mission is to ensure, through information, empowerment, and peer support, that no one faces breast cancer alone. Information is available in English, Spanish, Chinese, Russian, Tagalog, Korean, and Vietnamese.

Young Cancer Spouses ✿ ✿

www.youngcancerspouses.org

Brings together young spouses of adults with cancer to share information, support, and experiences.

X. Glossary of Common Cancer Terms

In addition to this list, you may want to use the online glossary found on the National Cancer Institute website at www.cancer.gov (search for “Dictionary of Cancer Terms”)

Acute: A sudden onset of symptoms or disease.

Adjuvant chemotherapy: One or more anti-cancer drugs used in combination with surgery or radiation therapy as a part of the treatment of cancer. *Adjuvant* usually means “in addition to” initial treatment.

Advance care directive: Specific instructions, prepared in advance, that are intended to direct a person's medical care if he or she becomes unable to do so in the future.

Analgesic: Any drug that relieves pain. Aspirin and acetaminophen are mild analgesics.

Anemia: A condition in which the number of red blood cells is below normal.

Antibody: A substance formed by the body to help defend it against infection.

Antigen: Any substance that causes the body to produce natural antibodies.

Aspiration: The process of removing fluid or tissue, or both, from a specific area.

Benign tumor: A swelling or growth that is not cancerous, does not spread from one part of the body to another, and is usually not life-threatening.

Biological therapy: Also called immunotherapy. Therapy with natural chemicals to kill or regulate growth of cancer cells.

Biopsy: A procedure where a piece of tissue or fluid (a group of cells) is taken from a person's body and examined with a microscope to see if the cells are normal or not. A biopsy is a common way of determining if a person has cancer and, if so, what type it is.

Blood cells: Cells that make up the blood. They are produced in bone marrow and consist of (1) red cells (which bring oxygen to tissues and take carbon dioxide from them), (2) white blood cells (which fight invading germs, infections, and allergy-causing agents), and (3) platelets (which are responsible for clotting).

Blood counts: The number value assigned to the major types of blood cells. Blood counts indicate the number of blood cells (red cells, white cells, and platelets) circulating in your bloodstream.

Bone marrow: The soft, spongy center of the bone. Bone marrow can be thought of as a “factory” that produces blood.

Bone marrow transplantation: A procedure in which doctors replace marrow destroyed by treatment with high doses of anticancer drugs or radiation. The replacement marrow may be taken from the patient before treatment or may be donated by another person. When the patient's own marrow is used, the procedure is called *autologous* bone marrow transplantation. When someone else's marrow is used, the procedure is called *allogeneic*.

Cancer: A general term for more than 100 diseases characterized by abnormal and uncontrolled growth of cells. The resulting mass, or tumor, can invade and destroy surrounding normal tissues.

Cancer fatigue: A certain type of fatigue associated with the cancer experience that has physical, social, and psychological impact.

Carcinogen: A substance or agent that is known to cause cancer.

Carcinoma: A kind of cancer that starts in the lining of organs.

Case manager: A person hired by your insurance company or hospital to evaluate your ongoing care.

Chemoprevention: The use of drugs to prevent cancer development or growth.

Chemotherapy: Treatment with anti-cancer medicines.

Clinical trial: Testing on a group of human subjects that utilizes existing, new, or experimental treatments for a particular disease.

Combination chemotherapy: The use of more than one drug during cancer treatment.

Computed tomography: Computer-generated cross-sectional images of a portion of the body. Also called *CT scan* or *CAT scan*.

Durable power of attorney: A legal document that lets you appoint someone to make health decisions for you if you become unable to do so for yourself.

Edema: Swelling or accumulation of fluid in a part of the body.

Excision: Surgical removal.

Fecal occult blood test: A test to check for hidden blood in stool. (*Fecal* refers to stool; *occult* means hidden.)

Follow-up care plan: Provides information about necessary post-treatment care, preventative practices, and resources for further information and support. It should include specific information about the timing and content of recommended follow-up (for example, screening tests for recurrences and/or secondary cancers, follow-up visits with the oncologist, etc.); recommendations about preventative practices and how to maintain health and well-being (for example, nutrition, exercise, and emotional support); information on employment rights as a cancer survivor and access to health insurance; and availability of support services in the local community.

Gene therapy: Treatment that alters genes (the basic units of heredity found in all cells in the body). Research in gene therapy is in the early stages of development. Researchers are trying to improve the body's natural ability to fight the disease or to make the tumor more sensitive to other kinds of therapy.

Grade (grading): A system used to categorize how quickly a tumor is likely to grow and spread. The grade of a tumor depends on how abnormal the cancer cells look under a microscope. Grading systems are different for each type of cancer.

Healthcare proxy: A person you appoint as your agent to make healthcare decisions for you if you become unable to do so for yourself.

Hematologic cancer: A cancer affecting blood-forming cells in the bone marrow, such as leukemia and multiple myeloma.

Hematologist: A doctor who specializes in the problems of blood and bone marrow.

Hormone therapy: Treatment that prevents certain cells from getting the hormones they need to grow, such as treating cancer cells to keep them from receiving hormones, or treating the glands that produce hormones, or surgery to remove glands that produce the hormones, such as the ovaries that produce estrogen, or the testicles that produce testosterone.

Hospice: Care for the terminally ill and supportive services for patients and their families.

Hyperalimentation: The intravenous administration of a highly nutritious solution.

Immune system: The complex group of cells and organs that defend the body against infection and disease.

Immunotherapy: Use of the immune system or the products of the immune system to control, damage, or destroy malignant cells (see *Biological therapy*).

Immunosuppression: Weakening of the immune system, causing a lowered ability to fight infection and disease.

Impotence: Inability to have an erection.

Infertility: The inability to conceive a child; sterile or barren. May apply to either a male or a female.

Informed consent: The legal standard that states that a patient must know certain risks and benefits before agreeing to undergo therapy.

Interferon: A type of biological response modifier (a substance that can improve the body's natural response to disease). It stimulates the growth of certain disease-fighting blood cells in the immune system.

Living will: A document that provides specific instructions about your healthcare treatment.

Leukopenia: A low number of white blood cells.

Long-term effects: Known or expected problems that may occur in persons who have received certain treatments.

Lump: A thickness under the skin that can be felt by the fingers, either by the person who has it or by a doctor. A lump can be a sign of cancer, but most lumps are not cancerous.

Lymphatic system: Spaces and vessels between body tissues and organs through which lymph, a clear fluid, circulates; the lymphatic system removes bacteria and other materials from tissues. Metastasizing cancer cells often appear in lymph nodes.

Lymphedema: A swelling of the arms and legs caused by surgery, radiation, or inherited abnormalities.

Lymph nodes: Small, bean-shaped organs located along the channels of the lymphatic system. Bacteria or cancer cells that enter the lymphatic system may be found in the nodes. Also called *lymph glands*.

Lymphocytes: White blood cells that kill viruses and defend against the invasion of foreign material.

Lymphoma: A type of cancer that starts in a lymph node.

Magnetic resonance imaging (MRI): A method of creating images of the body using a magnetic field and radio waves rather than x-rays. Although the images are similar to those of CT scans, they can be taken in all 3 directions rather than just in cross-sections.

Malignant tumor: A tumor that is cancerous.

Mammography (mammogram): A low-dose x-ray of the breast to detect abnormalities.

Managed care: An approach to healthcare that adds the cost of services to the model. Its goal is to provide high-quality healthcare at a reasonable cost.

Medical oncologist: A doctor who specializes in treating cancer with drugs (chemotherapy).

Metastasis: The spread of cancer cells from the original tumor through the bloodstream and lymphatic system to another part of the body. Metastasis also is the word used for a secondary tumor caused by this movement of cancer cells.

Neoplasm: A new growth of cells.

Neutropenia: A decreased number of neutrophils, a type of white blood cells.

Oncogenes: Genes that, when mutated, can advance the growth of cancer. When normal, these genes play a role in regulating the growth of cells.

Oncologist: A doctor specializing in the diagnosis and treatment of cancer.

Oncology: The study and treatment of cancer.

Oncology-certified nurse (OCN): A registered nurse who has met requirements and successfully completed a certification exam. An OCN provides and supervises care for cancer patients who are either chronically or critically ill.

Palliative treatment: Therapy aimed at relieving symptoms, not aimed at curing the disease.

Pathologist: A doctor who specializes in analyzing tissues, then communicating the diagnosis to the treating physician.

Prognosis: A prediction of what might happen in a specific case of disease.

Prognostic indicators: A situation, condition, or characteristic that can be used to estimate the chance of recovery from a disease or the chance of the disease recurring (coming back).

Protocol: A treatment plan.

Radiation oncologist: A doctor who specializes in using radiation to treat cancer.

Radiation therapy: X-ray treatment that damages or kills cells. The dose is recorded as Grays (Gy) or as Centigrays (Cgy).

Recurrence: The return of cancer cells and signs of cancer after remission.

Regression: Growing smaller or disappearing. A term used to describe shrinkage or disappearance of a cancer.

Relapse: Same as *recurrence*.

Remission: The disappearance of cancer symptoms; absence of evidence of cancer's existence. When this happens to a person, he or she is said to be "in remission."

Second opinion: Examination of a patient and/or patient's records by another doctor for an additional treatment recommendation.

Side effects: Problems that occur when treatment affects healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.

Site of origin: The part of the body where a cancer started.

Skin patch: A bandage-like patch that releases medication through the skin and produces a slow, steady delivery of medication into the bloodstream.

Sperm banking: Freezing sperm before cancer treatment for use in the future. This procedure can allow men to father children after loss of fertility.

Stage (staging): A system used to define the extent of spread of a cancer.

Surgical oncologist: A doctor who specializes in cancer surgery.

Survivor (as in “cancer survivor”): Anyone who has received a cancer diagnosis, whether treatment is being received or has been completed. Just as success is a journey instead of a destination, cancer survivorship also is a journey.

Systemic: Throughout the body.

Tissue: A group of cells.

Transcutaneous electrical nerve stimulation (TENS) unit: A machine that uses low-frequency electrical stimulation for relief of pain.

Transdermal: Through the skin.

Treatment plan: Indicates the diagnosis and outlines the goals and intended course of treatment, as well as possible side effects and plans to manage them. It should also include a psychosocial assessment, a discussion of advance directives, and a discussion of participating in a clinical trial, if appropriate.

Treatment summary: The record of treatment that actually took place, including the cancer diagnosis, the treatments received (including surgeries, the names and dosages of drugs and the dosages and frequency of radiation), and the patient’s response to them. Wherever possible, the potential long-term effects of treatments should be noted.

Tumor: Cells that group together and keep growing and crowding out normal cells. A tumor can be benign (not cancerous) or malignant (cancerous).

Tumor margin: The edge or border of the tissue removed in cancer surgery; described as negative or clean when the pathologist finds no cancer cells at the edge of the tissue, suggesting that all of the cancer has been removed; described as positive or involved when the pathologist finds cancer cells at the edge of the tissue, suggesting that all of the cancer has not been removed.

Tumor markers: Substances found in abnormal amounts in the blood, in other body fluids, or in tumor tissue of some patients with certain types of cancer.

Ultrasound: A diagnostic imaging technique using sound waves to create an echo pattern that reveals the structure of organs and tissues.

XI. Contributors

The Toolbox Team dedicates this edition of the *Cancer Survival Toolbox* to one of our original members, Debra Thaler-DeMers. While Debra was the consummate mother, sister, daughter, and friend, she was also a courageous survivor and exceptional oncology nurse. Debra dedicated her life to raising awareness about survivorship and advocating for quality cancer care.

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The following survivors’ pictures are on the cover of the Toolbox:

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The Cancer Survival Toolbox® Is an Award-Winning Program

The *Cancer Survival Toolbox* is designed to support all cancer survivors. If you find the Toolbox helpful, we encourage you to pass it on, when you no longer need it, to a friend or to your local library, community center, or house of worship, so that others may benefit from this information.

National Health Information AwardsSM Bronze Certificate, 2010

The National Health Information Awards recognize the nation's best consumer health information programs and materials. The Spanish version of the *Cancer Survival Toolbox* was awarded the Bronze Certificate in the Patient Education Information class in the Other/Miscellaneous category.

National Health Information AwardsSM Silver Certificate, 2009

The *Cancer Survival Toolbox* was awarded the Silver Certificate in the Total Health Information Program category.

National Cancer Institute Cancer Patient Education Network (CPEN) Gold Star Award, 2000

The CPEN Gold Star Award recognizes organizations or groups that have made outstanding contributions to cancer patient education. The 2000 National Cancer Institute CPEN Gold Star Award was given to the four organizations that produced the *Cancer Survival Toolbox*: NCCS, AOSW, ONS, and Genentech® BioOncology.

Public Relations Society of America Silver Anvil Award of Excellence, 2000

The *Cancer Survival Toolbox* won an Award of Excellence in the Corporate/Nonprofit Partnerships category of the Silver Anvil awards sponsored by the Public Relations Society of America. The Silver Anvil is the highest honor a public awareness campaign can achieve.

American Society of Association Executives (ASAE) Award of Excellence, 2000

The *Cancer Survival Toolbox* received honors in the ASAE Associations Advance America Awards. This award recognizes associations that propel America forward with innovative educational projects. The Toolbox received recognition in the category of Business and Social Innovation.

Women Executives in Public Relations (WEPR) Foundation Crystal Obelisk Award for Social Responsibility, 2000

The *Cancer Survival Toolbox* received the coveted Crystal Obelisk Award from the WEPR Foundation. The Crystal Obelisk is the only public relations industry award given solely for social responsibility.